

## Dementia awareness, beliefs and barriers among family caregivers in Pakistan

Article (Accepted Version)

Balouch, Sara, Zaidi, Asghar, Farina, Nicolas and Willis, Rosalind (2021) Dementia awareness, beliefs and barriers among family caregivers in Pakistan. *Dementia*, 20 (3). pp. 899-918. ISSN 1471-3012

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## **Dementia Awareness, Beliefs and Barriers among Family Caregivers in Pakistan**

Abstract word count: 300

Manuscript word count: 7115

By Sara Balouch<sup>1</sup>, Asghar Zaidi<sup>2</sup>, Nicolas Farina<sup>1</sup> and Rosalind Willis<sup>3</sup>

<sup>1</sup>Brighton & Sussex Medical School, Brighton, United Kingdom.

<sup>2</sup>Government College University, Lahore, Pakistan, Oxford Institute of Population Ageing, Oxford,  
United Kingdom.

<sup>3</sup>University of Southampton, Southampton, United Kingdom

Correspondence concerning this article should be addressed to Dr Sara Balouch, BPP University,  
School of Health, Department of Psychology, 137 Stamford Street, Waterloo, SE1 9NN; +44-208-  
334321; sarabalouch@bpp.com

## **Dementia Awareness, Beliefs and Barriers among Family Caregivers in Pakistan**

### **Abstract**

**OBJECTIVES:** Dementia research and services in Pakistan are limited. The following was explored in experiences of family caregivers of people with dementia in Pakistan: a) to determine whether culture and religion play a role in caregiving; b) to draw insights on how family caregivers cope, what barriers they face, and what help they would be willing to accept; and c) to determine how these findings could be used to raise awareness and influence public policies in improving the lives of families living with dementia.

**METHODS:** The experiences of family caregivers of people with dementia in Pakistan were explored via semi-structured interviews (10 in Lahore; 10 in Karachi). This was part of a larger qualitative study conducted about dementia in Pakistan. Caregivers interviewed were aged 35-80 (14 female). Most caregivers in the study were educated and affluent. Interviews were conducted in Urdu, translated into English and thematically analysed.

**RESULTS:** Five themes emerged: Knowledge & Awareness; Stigma; Importance of Religion and Duty to Care; Use of Day Care Centres and Home-help; and Barriers. A lack of dementia awareness exists in Pakistan. The religious duty to care for family influenced caregiving decisions. Day care centres and home-help were accessed and viewed positively. The caregivers also wanted extracurricular activities for people with dementia, support groups for caregivers, and better training for healthcare staff. Novel findings included that caregivers felt that dementia should not be stigmatized, and awareness should be raised in Pakistan via TV, radio and social media, but not inside mosques.

**DISCUSSION:** Additional research is necessary to determine if positive views of day care centres and home-help exist more widely. Attitudes and experiences regarding stigma may be different for caregivers of people with more advanced dementia. We recommend raising dementia awareness, allocating more funds to dementia services, and an emphasis on home-based care.

**Keywords:** Dementia, Caregiver, Care, Family, Awareness, Beliefs, Religion, Stigma, Barriers, Low and Middle Income Country

## Introduction

Dementia affects over 47 million people worldwide and this will rise to more than 131 million by 2050 (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016), making dementia a global health priority, especially in the resource constrained low and middle income countries (LMIC), such as Pakistan. It was estimated that 58% of the dementia population reside in LMICs and this is set to rise by 71% by 2050 (Alzheimer's Disease International, 2015). There are as yet no population-based reports of dementia prevalence in Pakistan (Shafqat, 2008). Pakistan is a Muslim majority, poor country and over half of the population are illiterate, negatively impacting the country's social and economic development (Rehman, Jingdong, & Hussain, 2015). The public healthcare system is generally of low quality, under severe population pressure, and its access is not evenly distributed (Khan, 2014). Healthcare specialists are often only available through private channels, accessible only by the wealthy (Shafqat, 2008). The social and economic rights of older people in Pakistan are poorly addressed (Zaidi, Stefanoni, & Khalil, 2019). In the Global AgeWatch Index 2015, Pakistan ranks low overall at 92 (out of 96 countries). It ranks particularly low in the health, enabling environment and income security domains (Zaidi, 2013)<sup>1</sup>. The 10/66 Dementia Research Group formed by Alzheimer's Disease International (Prince et al., 2003) has carried out significant research in many LMICs including India; however, dementia related social science research in Pakistan is virtually non-existent. For that reason, evidence to deal with the increasing numbers of people with dementia are sparse (Khan, 2014; Swaminathan et al., 2017). Notwithstanding the economic and educational shortfalls, there are layers of religious and cultural beliefs

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<sup>1</sup> The latest results of the Global AgeWatch Index for Pakistan are available at: <http://www.helppage.org/global-agewatch/population-ageing-data/country-ageing-data/?country=Pakistan>

that play a dominant role in people's awareness and attitude towards medical conditions and how people with medical conditions are cared for.

Due to the lack of formal care services in Pakistan, caregivers of people with dementia consist mainly of family members (Qadir, Gulzar, Haqqani, & Khalid, 2013). Family caregivers are under immense pressure, as they often sacrifice their own health and well-being to care for their family member. Research has shown that caregiver burden is related to diminished physical health (Schulz & Sherwood, 2008), depression (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014), poor quality of life (Riedijk et al., 2006) and increased financial burden (Wimo, Jönsson, Bond, Prince, & Winblad, 2013). Furthermore, a society's culture, beliefs and dementia awareness can have enormous implications on help-seeking and how care is delivered. Much of the research on dementia awareness and attitudes in South Asian people come from ethnic minority communities who live in Western countries. These studies show a general lack of knowledge and awareness of dementia, a sense that dementia is shameful and that it is the family's responsibility only (especially daughters and daughters-in-law) to care for people with dementia (Bowes & Wilkinson, 2003; Giebel et al., 2017; Hailstone, Mukadam, Owen, Cooper, & Livingston, 2017; Mukadam, Cooper, & Livingston, 2011; Parveen & Oyebode, 2018). Furthermore, although ethnic minority carers may feel obliged to care for their family, they may not be willing, be prepared or know how (Parveen & Oyebode, 2018). There are limited studies on attitudes and experiences of dementia in Pakistan (Ali & Bokharey, 2015, 2016; Khan, Khan, Khan, & Najam, 2017; Qadir et al., 2013). Ali and Bokharey interviewed eight caregivers of people with dementia in Pakistan on their experiences of dementia caregiving (Ali & Bokharey, 2015). They found high levels of stress, sleep disruption and fatigue, which were made worse by maladaptive thinking patterns. Ali and Bokharey later suggested an interaction between maladaptive emotions and behaviours, and how that might play a role in caregiver burden and quality of life (Ali & Bokharey, 2016). Qadir and colleagues found that caregivers in Rawalpindi/Islamabad lacked awareness of dementia, were conflicted by emotional and religious commitments to care and reported high psychological, physical and economic burden (Qadir et al., 2013). Finally, a survey of 38 members of the public took place at a free dementia

public awareness event in Pakistan (Khan et al., 2017). Eleven out of 38 identified themselves as having dementia and eight were caregivers of people with dementia. Khan et al. (2017) found that only half of the people with dementia and caregivers were aware of the type of dementia they or their family member had been diagnosed with. Memory loss was the most distressing symptom, followed by depression, anxiety and incontinence. Research is required to explore further experiences and knowledge of dementia in Pakistan, in order to influence public policy and increase dementia awareness in Pakistan.

Thus, the current study aimed to explore dementia awareness in Pakistan, how culture and religion play a role in caregiving, how caregivers cope, what barriers they face and what help they would be willing to accept based on the complexities of their cultural and religious values. Caregivers were recruited from two metropolitan cities in Pakistan, Karachi and Lahore. This allowed for a comparison across two provincial capitals of Pakistan with different socio-demographic and economic profiles. The services provided to family caregivers differ across these two towns. For example, one local hospital in Karachi offers various support services to help with managing dementia. Similarly, a non-governmental organisation (NGO) in Lahore set up the first day care centre in Pakistan for people with dementia. We are unaware of any other dementia services in Pakistan.

## **Methods**

### **Design**

This was a qualitative study, whereby data collection was carried out via face-to-face, semi-structured interviews. The study was part of a larger study exploring experiences of dementia in Pakistan (for further information see Zaidi, Willis, et al., 2019). This paper analyses only the interviews with family caregivers of people with dementia.

### **Ethical considerations**

This project was approved by the ethical review board of the University of Southampton [25793] and Aga Khan University [4819-Psy-ERC-17]. Full, informed, written consent was obtained from all caregivers interviewed.

## **Participants**

Twenty family caregivers of people living with dementia were recruited from two major metropolitan cities in Pakistan (10 from Karachi; 10 from Lahore). In Karachi, the staff at a local hospital identified potential participants through the clinic's register. The selected participants were then invited to take part in the study, either during a clinic visit or through a telephone call by staff at partnering organisation. In Lahore, an NGO providing information, training and services for those affected by dementia identified potential participants through their database of service users attending various activities supporting caregivers. The selected participants were invited to take part in the research through face-to-face interviews. No incentive was offered to participants to take part in the interviews.

## **Measures and procedure**

The research team was based in the UK and consisted of mostly researchers fluent in English. Thus all documents were initially created in English. This included the semi-structured interview guide (described fully in Zaidi, Willis, et al., 2019), participant information sheets and consent forms. These were subsequently translated into Urdu by the teams in Karachi and Lahore. Comprehension and accuracy of these documents was checked by Urdu fluent patients and caregivers in Pakistan in order to check the appropriateness of the wording, question order and relevance in the context of Pakistan. An Urdu-speaking member of the UK research team checked the final draft of the documents for accuracy.

The interview guide aimed to explore the following aspects: the first set of symptoms the caregiver noticed in the person with dementia, how these symptoms were understood by the family, the response the family made to these symptoms, their expectations for the future, the trigger to access to

health services, the help that was offered/received, the reaction of the community, and the disease prognosis understood by caregivers. The interview questions were used as a guide, but interviewers were encouraged to ask additional questions ad lib depending on what interviewees spoke about.

The interviews were conducted by members of two reliable Pakistani organisations who support people with dementia and their families. The interviews were carried out by experienced qualitative interviewers who live and work in Pakistan. The interviewers were briefed about the project, in particular about the ethics of obtaining consent for interviews from individuals with dementia and for the cultural and religious sensitivities. They were trained to use the study instruments by the research team.

Interviews were carried out during 2017 at a place that was convenient for the caregiver (e.g. place of work, home or the recruitment site). After informed consent was given, demographic information (e.g. caregiver age, sex, occupation, and relationship with the person with dementia) was recorded. All interviews were audio recorded using digital recorders, to allow for transcription and sharing of files between the research team. The audio recordings were transcribed verbatim in Urdu. These transcripts were then translated into English. Both Urdu and English transcripts (word documents) were electronically sent to the research team in the UK, where further quality checks on the translations were undertaken. The finalised English transcriptions were used by researchers for the analysis.

## Analysis

Co-investigators met prior to data analysis for training and guidance. One researcher coded all the caregiver transcripts (SB). All transcripts were read fully at least once and transcripts were coded in NVivo Version 11 (QSR International Pty Ltd, 2015). NVivo was used to organise and sort the textual data. Thematic analysis was used to analyse the data, whereby the themes that emerged were data driven, rather than theory driven (Braun & Clarke, 2006). The analysis followed six phases of thematic analysis, based on Braun and Clarke (2006): (1) reading and rereading the data, and noting down initial ideas; (2) generating initial codes or *nodes* (as is known in NVivo) in a systematic fashion; (3) merging nodes into themes; (4) reviewing themes and generating a 'thematic map' of the analysis; (5) refining



specifics of each theme and sub-theme in order to generate names and definitions for each theme; (6) writing the report.

During the coding process three co-investigators (NF, AZ, RW) independently reviewed transcripts and added to the existing coding scheme. Any disagreements were resolved through discussion. Co-investigators met again towards the end of coding for discussion and decision on overarching themes.

### **Analytic Rigour**

The Principal Investigator (AZ), who is of Pakistani Muslim origin, was present at some of the caregiver interviews and thus during the quality check of coding was able to ensure that meanings were not misinterpreted. Co-investigators were in regular communication with each other to discuss via email or in person any uncertainties in interpreting Pakistani culture, language and Islamic teachings that might affect coding. The lead author has an Iranian Muslim background, which shares similarities with the Pakistani culture, and she was able to draw on this knowledge for interpretation of the transcripts. The final coding and themes were discussed amongst the research team and were presented to the broader scientific advisory board (consisting of Pakistani clinicians and academics) to ensure validity of the findings.

## **Results**

### **Demographics**

Caregivers were mostly female in both cities (14 females overall). On average, male caregivers were 62 years old ( $SD = 14.21$ ) and tended to be older than the female caregivers ( $M = 48$  years,  $SD = 9.43$ ). Based on the information we have available on the caregivers' occupations; it appears that the caregivers interviewed were of high socio-economic status (SES). The caregivers were mostly partners of those people with dementia who were cared for. See Table 1 for a summary of demographic data.

Eight of the females and five of the males interviewed were receiving home-help (paid help for household chores and personal care to the person with dementia). Most caregivers mentioned that the person they were caring for was receiving or had previously received conventional pharmacological treatment (e.g. acetylcholinesterase inhibitors) for their dementia (7 from Lahore; 7 from Karachi), whilst 6 caregivers told us that the persons they were caring for were currently not receiving any treatment for their dementia (5 from Lahore; 1 from Karachi). It appears that most of the caregivers were looking after relatives with multimorbidities (6 from Lahore; 10 from Karachi). In other words, the participants with dementia in this study had been experiencing additional health conditions, diseases or disabilities (see Table 2).

[TABLE 1 HERE]

[TABLE 2 HERE]

## Themes

Five key themes were drawn from the data, namely: Knowledge and Awareness; Stigma; Importance of Religion and Duty to Care; Use of Day Care Centres and Home-help; and Barriers.

### **Knowledge and Awareness**

Nine (almost half) of the caregivers had not heard of dementia or Alzheimer's disease prior to diagnosis. K1 (female, Karachi) said, "*No, we never thought that 'what is this?', because I had no idea and I didn't know what is Alzheimer's.*" Only one caregiver (L2, female, Lahore) remained unaware that the person they were caring for had dementia, even after diagnosis. The reason for this lack of awareness may have been due to miscommunication between doctor and patient/family. Alternatively, the lack of

awareness may be due to miscommunication between family members. For example, L2 was the daughter-in-law of the person with dementia and perhaps the diagnosis was not communicated to her by other members of the family, e.g. her husband or father-in-law. Of note, a previous study showed that family caregiver characteristics that were linked to being unaware of a dementia diagnosis, included lower educational attainment, less functional impairment and attending doctor visits alone (Amjad et al., 2018), which may have also played a role.

Prior to the dementia diagnosis, caregivers had mistaken the early symptoms of dementia for a number of different anomalies, such as depression and dementia being a normal outcome of ageing. However, dementia symptoms were also mistaken for more obscure things, such as the adverse effect of eating Betel nuts and evil possession. Caregivers were asked what they thought caused dementia. To clarify, potential modifiable risk factors of dementia include: less education in early life, hearing loss, cardiovascular risk factors (e.g. hypertension and stroke), obesity, smoking, depression, physical inactivity, social isolation, diabetes and brain trauma. Age and the rare genetic allele, APOE-e4, are non-modifiable risk factors (Livingston et al., 2017). Thirteen caregivers attributed dementia to ‘tension’ (e.g. stress, shock or emotional trauma) as the most prominent belief. L1 (female, Lahore) said, *“It’s like we should take tension, but in our lives we can’t live with taking tension from everything. When we take tension, it puts pressure on our brain and leads to such diseases.”* Other similar beliefs included ‘thinking too much’ and the trauma and loneliness of missing family living abroad. Five caregivers attributed the cause of dementia to a lack of social interaction. K2 (female, Lahore) spoke of her husband with dementia not being able to relieve his stress, due to lack of social interaction. *“He did not have any social group where he could talk of things in his heart and get rid of stress. He did not do these things; maybe these things affected his brain.”* Eleven caregivers believed in a genetic link to dementia and some feared that they would also develop dementia. K6 (female, Karachi) said, *“....now I feel very much afraid because it is hereditary and now I have also become forgetful.”* However, two caregivers showed an awareness that although genes can play a role in some cases, this is not the only risk factor. Blood pressure and stroke were also correctly assumed as risk factors.

## **Stigma**

In contrast with other research on stigma of dementia in South Asian communities (Farina, Zaidi, Willis, & Balouch, 2019; Giebel, Zubair, et al., 2015), the caregivers generally believed that dementia was not taboo in their own families or their own SES class. They believed that dementia should not be hidden from others. L10 (male, Lahore) said, *“No. We felt no need to hide it and it isn’t a thing to hide really.”* However, our participants, who were generally high in SES, believed that amongst lower SES classes or less educated individuals in Pakistan that dementia, and mental illnesses in general, were a taboo. When asked whether memory and psychological issues were stigmatized in Pakistani society, K5 (female, Karachi) said, *“Not amongst the educated, they can differentiate between ‘what is mental illness?’, ‘what is depression?’, ‘what is dementia?’. Psychiatry...there will be psychological reasons [and] they hide from the people. Less educated and families that come from lower income groups cannot differentiate.”* Caregivers had mostly received positive reactions from the community. This was in the form of members of the community caring, being helpful, sympathizing, praying for the person with dementia, and being respectful and understanding. L1 (female, Lahore) said *“No why would they make fun. They feel bad that a person who was so outgoing and helpful is going through such an issue.”* Nonetheless, some caregivers had also received negative community reactions that included physical abuse, not caring, others making fun, others using stigmatizing language, others not visiting anymore, and others talking behind their backs or ‘back biting’. For example, L4 (female, Lahore) said, *“As people do not talk to your face, they just do back biting. I went to an event and the people present said that she has almost gone mad and I should try to keep her at home. So that’s why I stopped going anywhere. I won’t go there and nobody will talk about it.”* It is clear from this statement that stigma towards dementia does exist in Pakistan, even though the majority of caregivers in this study did not appear to hold these views themselves.

## **Importance of Religion and Duty to Care**

The caregivers identified themselves as Muslim and the duty to care for family members is believed to be a fundamental teaching of Islam. All caregivers felt they had a duty to care for other family members and disagreed that the caregiving was a burden: *“No I never think that he is burden for us...My parents told me one thing after marriage that taking care of your husband is your prime responsibility and take it as Jihad [a personal struggle in devotion to Islam], so I take it as my responsibility....”* (K8, Female, Karachi). Caregivers also believed that God would reward them for looking after their relative. L1 (female, Lahore) said, *“Yes obviously God will reward us for this.”*

The duty to care for family remained strong even when caregivers were affected adversely by the caregiving. For example, 11 women and three men spoke about difficult behaviours and emotions such as aggression and anger in the person they were caring for. L4 (female, Lahore) spoke about caring for her sister: *“Everything is difficult. She is an Alzheimer’s patient. She kicks on my chest, on my face. She kicks so hard that it gives me an excruciating pain and still I don’t mind it.”* The caregiver accepts her caregiving role, without complaint, even when physically abused. The high number of caregivers experiencing difficult behaviours from the person they are caring for in this study is a cause for concern, but this is not an uncommon experience amongst people with dementia. Approximately 40% of people with dementia exhibit aggressive behaviour (Morgan et al., 2013). This, coupled with our participants’ belief that caregivers must endure this distress and potential trauma due to religion and/or culture, becomes a serious concern. Difficult behaviours can be managed via many non-pharmacological interventions, such as reducing fatigue in the person with dementia, reducing overwhelming environmental stimuli, managing pain, managing routine, and interventions focusing on caregiver coping mechanisms (Wharton & Ford, 2014). Furthermore, pharmacological interventions can be used in severe cases (Kindermann, Dolder, Bailey, Katz, & Jeste, 2002). Thus, greater awareness about difficult behaviours in dementia and education on how to manage these symptoms, in a way that is sympathetic to the caregivers’ religion and duty to care, would be beneficial for caregivers of people with dementia in Pakistan.

As a result of the beliefs and duty, relying on a care home or nursing home to look after a relative was considered shameful by our participants. When asked about nursing homes, K5 (female, Karachi) said, *“It is for those who have nobody to look after and care for them. Obviously, it’s a way out.....it is very disgraceful for us to use a nursing home and that too for the elderly people. For me, things like this, is very insulting.....There is [Divine] order for the children regarding how they should live with and take care of their mother and father and other elderly people.”* From this quote, it is clear that K5 held the view that people whose older relatives resided in nursing homes were looked down upon.

### **Use of Day Care Centres and Home-help**

Six caregivers interviewed had accessed one of two day care centres in Karachi and Lahore. Five of these caregivers had accessed the day care centre in Lahore and had positive experiences and views of the centre. These caregivers felt that the day care centres were helpful to both the people with dementia and the family caregiver. They also stressed the importance of day care centres in the early stages of dementia. L4 (female, Lahore) said *“Yes, we used to take her to the day care centre. She felt very relaxed there. She was engaged in different activities...She was happy, and the main thing is that due to the activities she had to do there, she came home tired.”* When the interviewer asked L4 if it was better for her too, she said: *“Yes, Because I could go to market during that time and do my work.”* The other caregiver, had a negative experience of the day care centre and felt that the staff there were not taking good care of her husband. This negative experience may have been an isolated experience. Alternatively, maybe the specific day care centre in question in one city was poorer quality than the day care centre in the other city.

‘Attendants’ or home-help (i.e. hired individuals to aid household chores and/or care for the person with dementia) were employed by six caregivers in Lahore and seven in Karachi. Almost all the male caregivers had received home-help (5 out of 6), but approximately half of the females had accessed home-help (8 out of 14). K3 (male, Karachi) recounts what happened to his wife when his children

moved abroad: “...her mental condition became worse. So, some of my relatives advised me to appoint attendant for her who will take care of her because they said that it’s not possible for you and us to look after her.....So that’s why I have appointed attendant. There are two attendants one for day and one for night, and she is the day attendant. Both are very helpful and I am so much thankful to both of them.” It is difficult to make gender comparisons with such small participant numbers; however, it appears that male caregivers may have relied on home-help more often than female caregivers. This finding is supported by a systematic review on the attitude of male caregivers in North America towards accessing formal and informal support (Greenwood & Smith, 2015). Male caregivers were reported to prefer formal support over informal support. Although, this finding in the North American context appears to be in line with our findings, we recommend future research on this issue for caregivers in South Asia.

## **Barriers**

At times, caregivers had not received sufficient support or treatment for their relative with dementia. The interviews provided insights on the barriers to accessing support and treatment.

**A lack of resources:** The most prominent barrier expressed by 16 caregivers (8 from Lahore; 8 from Karachi) was a lack of resources. This included limited funds, no transportation, a lack of support services, a lack of dementia-friendly adaptations, doctors being too busy, and unavailable treatment. L8 (male, Lahore) explained why he could not take his wife with dementia to the day care centre, “*Like she cannot climb up or down the stairs, so how can we take her there?*” Eight caregivers wished for more day care centres or organised day activities to not only stimulate the person with dementia, but also to provide some respite to the caregiver. They also wanted the day care centres to be easy to travel to:

*“....there must be a day care centre within the walled city of Lahore so that if people do not have a transport facility, there must be a place where people should get together and talk about it. And it should not be a single day care centre. There should be a number of different day care centres in every area so that people who cannot go far can have access to them. And so people can go there on foot.”* (L4, Female, Lahore).

Five caregivers (all female; four from Lahore) wished for more dementia support groups, either in person or online. K5 (female, Karachi) mentioned how there are support groups for people living with autism and diabetes, but not many for dementia: *"...I have seen people with Autism or other problems; they have support groups which are very helpful. You learn to deal and learn from others' experience. You learn a great deal because you are going through these. There should be support groups; there is for Diabetes. There should be [support groups] in this...."* Six caregivers (five in Lahore) wanted to see better training for healthcare staff. L3 (male, Lahore) said, *"I think the caregivers in Pakistan are not particularly trained for Alzheimer's. If it was up to me I would like to provide a service that has properly trained caregivers, who are not only trained psychologically and mentally, but also physically."*

Thus, it is clear from these interviews that the caregivers in this study felt they did not have enough formal support and that this is something they wished for.

**Mistrust of formal support:** In contrast, some caregivers were reluctant to receive support from outside of the family, as they worried about the quality of the care (including some of those who had received home-help). They did not believe that the care from outsiders could be as good as the family care. L9 (female, Lahore) said, *"Only those people can care for you, who actually feel anything for you."* In some instances, the person with dementia had refused formal care. L1 (female, Lahore) recalled a time when her mother-in-law with dementia refused home-help: *"I hired a maid once for helping her in bathing. She got very hyper after seeing the maid and starting beating herself. She hit herself so much that her body got bruised. She said 'why you called this maid over?'"* Thus, although some caregivers expressed a need for formal care, the persons with dementia were sometimes resistant to this support.

**A lack of awareness:** A lack of dementia awareness led two caregivers to delay treatment for the person with dementia, because they were either scared of the diagnosis or they thought the condition



would get better naturally. Seven caregivers were unaware of any day care centres, even though they lived in a city with a day care centre. All caregivers believed that raising awareness of dementia was necessary in Pakistan and the most common suggestions on how to do this was through online/social media, TV/radio and printed media. K4 (female, Karachi) said, “...like social media that informs that what it is, what kind of disease it is. I have read and learnt a lot of things relating to the disease of my mother-in-law from the Internet. My husband has also read about it.” L1 (female, Lahore) said “What could be done is that a TV commercial could be run.”

Interestingly, when caregivers were asked how dementia awareness could be raised in Pakistan, only two caregivers thought mosques would be an appropriate platform for raising awareness. Five caregivers felt it was not an appropriate place for raising awareness about health issues or had doubts about it. The reasons given were that women rarely attend mosques, mosques are for character building not for health issues, and mosques are “tangled in their own problems” (L8, male, Lahore). Furthermore, L4 (female, Lahore) recalled a time when an ill person was trying to raise money for their treatment in a mosque, but nobody was listening: “I think hardly anyone helped him out. Nobody listens.” Thus, L4 had no confidence in using mosques as a platform for raising awareness.

## Results Summary

Overall, the findings reveal that almost half of the caregivers had not heard of dementia prior to diagnosis. Most caregivers experienced positive reactions from the community, although some also received negative stigmatised reactions. Caregivers believed stigma regarding dementia should be eliminated. Islam played an important role in the caregivers’ beliefs about caring for their family - mainly that it was their duty to look after their family, even when faced with difficult behaviours from the persons they were caring for. Furthermore, using care homes was considered shameful. However, day care centres and home-help were more readily used to aid caring. The caregivers identified a number of barriers to receiving support or treatment. They included a lack of resources, mistrust of formal support, and a lack of awareness of dementia or dementia services. The most common suggestions

caregivers gave on how to raise awareness in Pakistan was through TV/radio, online/social media and printed media. They generally did not welcome raising awareness within mosques, although this does not rule out the possibility of mosques working together with not-for-profit organisations and medical practitioners to raise awareness within the community.

## Discussion

In this qualitative study, we explored the knowledge, beliefs and experiences of dementia family caregivers in Pakistan. We found that the caregivers interviewed had some prior knowledge of dementia. However, there were inaccuracies in their knowledge, often attributing dementia to stress, and many had not even heard of dementia or Alzheimer's disease prior to the diagnosis. There was an overwhelming belief from the caregivers that Pakistani people in general had little or no awareness of dementia. These findings are in line with South Asians living in the UK who have shown to have less basic knowledge about dementia than their White-British counterparts (Blakemore et al., 2018). Also, this supports previous findings from the study of caregivers of people with dementia in Rawalpindi/Islamabad, Pakistan, who showed very little or no knowledge of dementia (Qadir et al., 2013). Judging by the caregivers' occupations, the caregivers appeared to be wealthy and well-educated. Most likely this was a facilitator for the diagnosis of dementia in the first place and their selection for our interview. Otherwise, we know from the findings of the other studies that many people with dementia in Pakistan may never receive a diagnosis, due to lack of dementia awareness and funds to access healthcare (Shafqat, 2008; Swaminathan et al., 2017). The government in Pakistan needs to facilitate a national campaign to raise awareness about dementia, in terms of how to identify it, what the risk factors are and how to seek help.

Interestingly, the caregivers interviewed did not believe that dementia should be taboo or kept secret. Indeed, many had experienced support, care and love from members of the community. In

contrast, previous research of South Asian communities in other countries (Mackenzie, 2006) and Islamic communities (Abojabel & Werner, 2016; Navab, Negarandeh, Peyrovi, & Navab, 2013) have reported high levels of stigma surrounding dementia. Although stigma was experienced by the caregivers in our study, there appears to be a shift in attitude towards dementia: caregivers viewed stigma as something that is not acceptable and needs to be eliminated. Many of the caregivers identified themselves as educated or of a higher class. They believed that stigmatizing thoughts and language only existed in the lower classes or the uneducated. Although this is merely their opinion (and is potentially showing discrimination towards so called, 'lower class' or 'uneducated' people), it is in line with research showing that stigma is more likely to exist where there is little understanding and awareness of dementia (Alzheimer's Disease International, 2012; Werner, 2014). This further supports the need for raising dementia awareness in Pakistan, especially in lower SES communities. Furthermore, stigmatization may not have been experienced, because caregivers have been caring for relatives in the milder stages of dementia. Earlier symptoms of dementia (e.g. forgetting appointments) may go unnoticed to the community, as opposed to more advanced symptoms (e.g. being unable to carry out everyday tasks). Thus, future research should aim to interview caregivers in more deprived areas and caregivers of relatives with advanced dementia.

In line with previous research (e.g. Shaji, Smitha, Lal, & Prince, 2003), the religious duty to care for family greatly influenced how persons with dementia were cared for, in the sense that they were cared for at home and nursing homes were generally frowned upon. This finding is unsurprising, because Islam, as with many other religions, places great emphasis on family duties to care for older relatives, especially for those in sickness (Rodwell, 2001). Worryingly, caregivers upheld this duty to care even when they experienced aggressive behaviour from the person they were caring for. As a result, health care practitioners should educate caregivers on treatment and coping strategies designed to manage aggressive behaviour, in a way that is sympathetic to the caregivers' religion and duty to care.

Interestingly, day care centres and home-help were accessed and often viewed positively by those who used them. This appears to be a sound strategy to cope with the strains of caregiving, without abandoning their duty to care. Indeed stigma surrounds institutional or residential care in Islamic communities (Abdullah, 2016) and nursing homes are viewed as a cause of deterioration of an older person's health, but hired help to support care in the home is an acceptable compromise (Dar al-Ifta al Misriyyah, 2018). Our caregivers viewed nursing homes as 'insulting' to older adults or to be used only as a last resort when an older person has no family. Nonetheless, extra help in the home was considered a more practical solution for the busy housewife caring for her father-in-law and trying to manage childcare and household chores, or for the retired man caring for his wife, because all his children had emigrated abroad. Indeed, most of the male caregivers in this study had taken on home-help and this is most likely an indication that the Pakistani men in this study were not accustomed to taking on the household and personal care duties. This may be because in South Asia, particularly in Pakistan, gender stereotypes and inequalities around the responsibility of household duties continue to exist (Islam & Asadullah, 2018; Strachan, Adikaram, & Kailasapathy, 2015). It also supports research suggesting that male caregivers in Western countries are more likely to seek formal support than informal support (Laditka, Pappas-Rogich, & Laditka, 2001; Zodikoff, 2007). Thus, future research that directly focuses on gender differences in accessing support services in Pakistan would be worthwhile. Furthermore, caregivers may have not wanted to use a nursing home through fear of stigmatization, similar to recent findings of South Asians living in the UK (Giebel, Challis, & Montaldi, 2015). Therefore, taking on home-help may have been an option with less stigma attached to it.

As expected, lack of resources (e.g. lack of funds, dementia services and access to transportation) is experienced in Pakistan creating a barrier for some caregivers and people with dementia receiving support or dementia treatment. The caregivers spoke specifically about how they wanted more day care centres within easy reach, as their current day care centre was very far from their homes. They also wanted extracurricular activities for people with dementia, support groups (either online or in person), and better training for healthcare staff. Caregivers viewed day care centres and any extracurricular (or

leisure) activities for the person with dementia positively. These were thought to be cognitively and/or socially stimulating for the person with dementia, and important for family caregivers to allow respite and time to continue with other responsibilities, such as child rearing. Research in Western countries supports the notion that leisure activities protect against cognitive decline (Wang, Xu, & Pei, 2012), improve patient well-being (Nyman & Szymczynska, 2016) and that day care centres relieve caregiver burden (Tretteteig, Vatne, & Rokstad, 2017). Thus, home-help and day care centres should be more readily available for people with dementia in Pakistan, as these are more likely to be harmonious with the beliefs and culture of Pakistani families. However, home-help and day care centres alone may not be sufficient to cope with the rise in population and older people living longer, thus care homes will become a necessity and public attitude surrounding this issue needs to change. Raising awareness in collaboration with religious leaders and health practitioners could facilitate this change. In Kuwait, an Islamic country, a successful social welfare support was provided in residential care to 43 older persons without compromising religious and cultural values (Al-Dhafiri, 2014). The residential care provided good quality care, leisure activities and socialising, which was not possible in their homes. Family contact was also maintained. Participants showed improved quality of life, positive views of residential care and improved meaning to their lives. Although Kuwait is a much richer country than Pakistan, this care provision is an example where public perception surrounding care homes can change, without compromising religious values, but funding is sorely needed.

In addition to a general lack of dementia awareness, there was also a lack of awareness about existing public health care services, which prevented early diagnosis or delayed seeking support or treatment. All caregivers felt a need to raise dementia awareness in Pakistan, mostly through social media, TV and radio. Some studies have suggested using mosques as a platform to raise awareness of dementia (e.g. Abdullah, 2016; Qadir et al., 2013). However, this was not an idea that was overly welcomed when proposed to our caregivers. One interesting point was that women do not attend mosques as much as men; therefore, half the population would not be reached. Others felt that it was not really the mosque's place to be communicating issues on health. This finding contrasts previous studies

that benefitted from raising awareness in mosques. For example, a cardiovascular prevention campaign that took place in mosques in Austria successfully raised awareness of cardiovascular disease risk factors in Turkish migrants (Bader, Musshauser, Sahin, Bezirkan, & Hochleitner, 2006). In Pakistan, perhaps rather than raising awareness within mosques, the government or not-for-profit organisations, such as Alzheimer's Pakistan, could work together with religious leaders to raise awareness in more accessible and more appropriate areas in the community, such as an educational stall in a shopping area, schools or places of work. A successful example of this is a study in Bangladesh (Rifat et al., 2008) that raised awareness of tuberculosis (TB) detection through a number of different community-based activities: by raising awareness in popular theatre performances; by teaching primary school pupils how to detect tuberculosis within their family; by Muslim religious leaders raising awareness on TB diagnosis and care in their Friday prayers at local mosques; by setting up "TB Clubs" that consisted of successfully treated patients who helped to identify new TB patients in the community; and through TB messages that were broadcast during popular programs on television. Thus, it may not be sufficient to raise awareness through mosques alone – these should be combined with community-based activities similar to previous research as reported above.

An additional barrier to accessing dementia care was a mistrust of health care services. Medical mistrust is related to patients' attitudes, satisfaction with care, compliance, desire to seek second opinions and disputes with physicians (Hall, Camacho, Dugan, & Balkrishnan, 2002). A recent meta-synthesis of barriers and facilitators in accessing dementia care by ethnic minorities (living in USA, UK, Australia and Canada) found medical mistrust to be a barrier to accessing care (Kenning, Daker-White, Blakemore, Panagioti, & Waheed, 2017). Kenning and colleagues found that there was a general mistrust of health care services and conventional medicine amongst ethnic minorities living in predominantly White, English speaking countries. Mistrust plays a key role in the process of care and studies have shown medical mistrust to be associated with disparities in a number of different health outcomes (Bergamo et al., 2013; LaVeist, Isaac, & Williams, 2009). For example, a previous study in ethnically diverse women

in the USA showed that medical mistrust reduces healthy behaviours, such as vaccination and screening (Kolar et al., 2015). However, these studies are related to ethnic minorities living in Western countries. We may not be able to relate these findings to people of the ethnic majorities in Pakistan. Furthermore, the participants from ethnic minority communities in these studies were diverse and should not be grouped together. Additionally, medical mistrust was not formally measured in the present study, however, the caregiver interviews alluded to a potential mistrust of health care services. Further research on mistrust and health care disparities in Pakistan would be a worthwhile avenue to explore, in order to determine the role that medical mistrust plays in decisions to care for family in Pakistan. If found to play a significant role, then trust can be built through national campaigns and health care services could reach out to the people with dementia and their families through public engagement events within communities.

A key limitation to this study was that our sample included caregivers who appeared to be relatively educated and financially unburdened, which means that we know very little about dementia experiences in poorer communities within Pakistan, who make up most of the population (Barry, McGuire, & Porter, 2015; Zaidi, 2013). Caregivers within poorer communities are more likely to have not sought a diagnosis for their relative with dementia due to lack of awareness of symptoms and the lack of funds to visit a doctor, and for the same reasons making it difficult to recruit these caregivers into research (Shafqat, 2008; Swaminathan et al., 2017). Nonetheless, this study provides important insights into the lives of family caregivers looking after persons with dementia in Pakistan. In future, more rigorous, large-scale studies, such as the 10/66 project (Shaji et al., 2003), will be necessary, including those in more deprived areas in Pakistan. Based on the present study, it can be recommended that a) the Pakistani government raise awareness of dementia on a national scale; b) more funding should be made available for affordable, visible and accessible specialist dementia services, such as day care centres, dedicated hospital wards, staff and support groups; and c) a greater focus should be placed on help in the home, as families in Pakistan are more likely to accept and benefit from home-based care.

To summarise, future research should aim to explore attitudes, experiences and beliefs of caregivers in more deprived areas of Pakistan and caregivers of relatives with severe dementia. Medical mistrust and gender differences in accessing support services should be directly studied in order to further tease out barriers to accessing support. Any dementia awareness campaign would need to take the nature of these barriers into account.

### **Acknowledgements**

The authors wish to thank all of the people who took part in the interviews for generously sharing their time and experiences. We also wish to thank our project partners in Pakistan without whom this project could not have taken place. We are grateful for the encouragement and support from Chris Roles (Chief Executive Officer of Age International) and Yasmin Rashid (Minister of Punjab for Primary and Secondary Healthcare, and Specialized Healthcare and Medical Education).

### **Declaration of Conflicting Interests**

The Authors declare that there is no conflict of interest

### **Funding**

This work was supported by Age UK, Age International, and HelpAge International [UoS ref: 17930-02].



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# Tables

**Table 1.** Summary of caregiver demographics

	Lahore		Karachi	
	Male	Female	Male	Female
<b>N</b>	4	6	2	8
<b>Mean age (range)</b>	56 (45-72)	45 (35-54)	74 (68-80)	50 (35-62)
<b>Occupation type</b>				
Housewife/husband or unemployed	0	5	0	6
Professional	0	1	0	1
Managerial	1	0	0	0
Clerical	0	0	0	1
Sales	0	0	0	0
Mechanical	1	0	0	0
Service	1	0	0	0
Operators	0	0	0	0
Farming	0	0	0	0
Retired <sup>1</sup>	1	0	2	0
<b>Relationship to person with dementia</b>				
Partner	2	2	2	4
Offspring	2	0	0	1
Daughter-in-law	0	3	0	1
Other relative <sup>2</sup>	0	1	0	2

<sup>1</sup>'Retired' included retired professor, lawyer, and district education officer; <sup>2</sup>'Other relative' included sister, sister-in-law and niece.

**Table 2.** Number of people with dementia who have multimorbidity, and type of dementia treatment and care they have received or are currently receiving

	Lahore	Karachi
<b>Multimorbidity<sup>1</sup></b>	6	10
<b>Treatment</b>		
Conventional treatment <sup>2</sup>	7	7
Alternative treatment <sup>3</sup>	3	1
Currently no treatment <sup>4</sup>	5	1
<b>Care</b>		
Accessed dementia healthcare	9	10
Support from family	9	9
Received home-help	6	7

<sup>1</sup>Multimorbidity included any other disease or health condition that the person with dementia had in addition to their dementia; <sup>2</sup>Includes all people with dementia currently on conventional treatment and those who previously received treatment. Conventional treatment included medication prescribed from a doctor specifically for dementia, e.g. anticholinesterase inhibitors; <sup>3</sup>Includes all people with dementia currently on alternative treatment and those who previously received treatment. Alternative treatment included herbal or natural remedies, homeopathy, allopathic medicine, and alternative therapy, such as Reiki. <sup>4</sup>Currently not on any treatment for dementia, but may include those previously on treatment.